ALL ALS

ACCESS FOR ALL IN ALS

Advancing the Future of ALS Research

About Us

ALL ALS Research Consortium brings together a dedicated community of researchers, people affected by ALS, government agencies, industry leaders, and non-profits to work towards finding treatments for ALS. Funded by the National Institutes of Health, this nationwide initiative is gathering critical clinical data and samples from participants including those living with ALS, at genetic risk, and others to accelerate research and ultimately improve the lives of those affected by this devastating disease.

Be part of the progress. Together, we can make a difference.

PREVENT ALL ALS

The PREVENT study is recruiting participants to explore the natural history of ALS, focusing on its earliest signs in asymptomatic ALS gene carriers. This research aims to enhance our understanding of the disease, paving the way for more targeted and personalized drug development. By advancing these efforts, the study brings us closer to the goal of halting, repairing, and preventing ALS.

Who can participate in the PREVENT study?

- Age 18 years of age or older
- Capable of providing informed consent
- Willing to follow study procedures
- First-degree relative of a known carrier of any ALS causative gene (including either symptomatic ALS/Frontotemporal dementia (FTD) patients or asymptomatic ALS gene carriers)
- First-degree relative of an individual with a compelling history of ALS and/or FTD causative gene with a compelling family history of genetic ALS involving at least 2 close relatives with ALS or FTD, at least one of whom had ALS.
- Access to a smartphone or tablet, and internet (need not be in the home – access to a public library or other available computer with internet connection is sufficient)

ASSESS ALL ALS

The ASSESS study combines a longitudinal natural history study and biomarker collection for ALS. It aims to make ALS research inclusive and accessible to everyone, including those who cannot visit academic medical centers, through new technology that allows remote participation. We are looking for people currently living with ALS, individuals who do not have ALS, are not known ALS gene carriers, or at risk of carrying an ALS causative gene to help researchers gain a deeper understanding of ALS and improve future clinical trials.

Who can participate in the ASSESS study?

- Individuals currently living with ALS
- Control participants including:
  - Individuals without ALS or known ALS gene mutations
  - Spouses or family members of ALS patients who tested negative for ALS gene mutations
  - General population or others encountered at ALS sites
  - Must not be at risk of carrying a causative ALS gene mutation

Participation Benefits:

Both PREVENT and ASSESS study may not provide direct benefits to participants, but aim to generate data that could benefit individuals with ALS. The studies focus on developing digital technologies and remote data collection to improve clinical trials and reduce clinic visit burdens. Collected samples and data will be stored in a central repository for use in future research.

Frequently Asked Questions

What sites offer the ASSESS and PREVENT studies?

The All ALS Consortium offers the ASSESS and PREVENT studies through its two coordination centers and 35 research sites across the United States. Visit the website for a list of site locations for onsite participation or contact our site coordinators for information about remote opportunities.

What should I expect when participating in this study?

In PREVENT, you'll complete annual in-person visits and quarterly remote visits for up to 3 years, providing blood and optional CSF samples. You'll also fill out online questionnaires and perform speech tasks, with an option for genetic testing and counseling.

In ASSESS, you'll have in-person or remote visits every 4 months or annually for up to 2 years. You'll provide blood and optional CSF samples, complete online questionnaires, and perform speech tasks.

How will my data and/or samples be used?

Your data will be stored in the NeuroBANK® system and may include personal information such as contact details and protected health information. Data will be shared with vendors for study activities and with researchers for future scientific projects, while ensuring deidentification of sensitive information. Genomic data, speech samples, and biosamples may also be shared with other researchers under strict data sharing agreements.

Will participants be compensated?

Study participants will be compensated in both studies. Reach out to the site study coordinator for more information about stipends for research activities.

Contact Us

To learn more about participating in the ALL ALS research program and to find a list of study locations, please visit our website or email us.

https://www.all-als.org/ info@all-als.org